

**GOVERNOR'S ADVISORY COUNCIL FOR EXCEPTIONAL CITIZENS (GACEC)  
GENERAL MEMBERSHIP MEETING**

***7:00P.M., February 19, 2019***

**George V. Massey Station, Second Floor Conference Room  
516 West Loockerman Street, Dover, DE**

**MINUTES**

**MEMBERS PRESENT** Susan Campbell, Nancy Cordrey, Cathy Cowin, Bill Doolittle, Ann Fisher, Beth Mineo, Robert Overmiller, Jennifer Pulcinella and Kimberly Warren.

**OTHERS PRESENT: Guests:** Dawn Alexander/Colonial School District, Maureen Whelan/Department of Education (DOE), Cara Wilson/Disabilities Law Program for Laura Waterland and Sarah Marlowe, GACEC applicant.

**Staff present:** Wendy Strauss/ Executive Director, Kathie Cherry/ Office Manager and Sybil Baker/ Administrative Coordinator.

**MEMBERS ABSENT:** Karen Eller, Terri Hancharick, Tika Hartsock, Emmanuel Jenkins, Thomas Keeton, Dana Levy, Carrie Melchisky, Mary Ann Mieczkowski, Brenné Shepperson, Howard Shiber, Deanna Tyree, and Laura Waterland.

Chair Ann Fisher called the meeting to order at 7:05. Ann asked for and received a **motion to approve** the February meeting agenda. The **motion was approved**.

**Public Comments**

Dawn Alexander from Colonial School District came to discuss her May 2018 visit with GACEC and her concerns with Child Development Watch (CDW). She stated that back in May, the GACEC voted to send a letter to the Governor recommending moving Part C out of DHSS and into DOE. It is her understanding that the letter has not been sent. She asks that the letter be sent. She shared a letter that was sent to the Governor from the Vision Coalition recommending aligned governance within early childhood. She shared that for those who are not aware we are currently in a system where our birth to five programming is under three different departments, which makes it difficult because there are three different systems being followed which means three sets of policies. She asked that GACEC recommend to the Governor that united governance be considered for all early childhood. She also asks that Council consider looking at Child Development Watch (CDW) and making recommendations about CDW because in the policy manual for CDW for instance, it outlines policy on developmental screening, which is not being done. The manual and IDEA statute and Delaware Code all state that all people working with children birth to three are to be licensed or certified in the state of Delaware, meaning they would be in DEEDS or DPR. However, over 50 percent of the staff working with children birth to three thru CDW are not certified or licensed in the state of Delaware. Lastly, she asked the GACEC to consider legislation that all staff who are going into homes from CDW providing

evaluations for children must have background check. Right now there are no background checks required. Dawn stated that she is happy to share any documentation with Council if they wish.

Ann asked for and received a motion to approve the January minutes. **The motion was approved.** She asked for and received **a motion to approve the January financial report. The motion was approved.**

### **CHAIR/DIRECTOR'S REPORT**

Wendy shared that the GACEC Joint Finance Committee (JFC) meeting went well but we won't know anything until June so we will keep you posted. The JFC hearings scheduled for tomorrow have been cancelled due to snow. The Heart 2 Heart Hugs campaign distribution took place on February 14, 2019. Wendy shared that over 4500 articles were distributed. Delaware Care donated over 500 homemade items and Project Warm donated 800 coats. We are having a meet and greet with some of the new legislators on Monday at 10 am at the GACEC offices. We have four new legislators confirmed. Wendy asked that Council members attend if they can. We will be giving an overview of what the GACEC is and what it does. Robert let staff know that there are 15 new legislators not 12. Sybil shared that she would go back and check her list to make sure no one was left off. Wendy's last item was about Boundless the musical. The play is now available on YouTube and there will be a hard copy of the video given to the cast members.

Ann reminded committee chairs that reports are to be turned in prior to leaving this evening.

### **DOE REPORT**

Mary Ann Mieczkowski was absent so there was no DOE Report this evening.

### **COMMITTEE REPORTS**

#### **INFANT AND EARLY CHILDHOOD**

Jennifer reported that the committee did not have a speaker this month but that they discussed the process of transitioning from Part C to Part B. She shared that they are prepared to meet with CDW next month regarding their noncompliance and what steps they are taking to become compliant. She asked if the report from the Birth -3 focus groups had been shared yet. Sybil stated that the group had been sent some initial information and asked to provide feedback but no final report had been issued. Sue Campbell advised that she would follow up to find out when it would be released though she thought it would be soon. Once it is received it will be shared.

## **ADULT TRANSITION SERVICES**

Maureen Whelan of DOE presented to the committee on the prison education system. Some statistics presented were: July 1 2018 to January 30, 2019 there were 94 students eligible. Of those students, 45 had an IEP. Four inmates participated without special education services and 45 did not want educational services at all. Classifications of students included 33 emotional disturbances, 40 learning disability 10 mild intellectual disability and 17 Other health impaired. Student outcomes included one regular diploma and two diplomas of alternate standards were issued. This report is NOT the end of the year report. Those numbers will be higher in the end of the year report. Cathy went on to say that she, as well as Nancy Cordrey have some concerns about the Lifespan Waiver. She stated that one size does not fit all, if they are understanding correctly, and that it is very hard to get accurate and consistent information. In order to get services through the Division of Developmental Disabilities Services (DDDS) like supported employment, the individual has to qualify for Medicaid. This means you cannot have assets of greater than 2000 and cannot make more than 1885 per month in salary. Discussion ensued about individuals who because of those qualifications, would no longer qualify for services, but would not be able to live in the community without them. There seems to be confusion because the information that is being given is inconsistent at best. Further discussion ensued regarding the individual circumstances of Cathy's and Nancy's adult children. Ultimately the feeling is that there is inconsistent information, lack of communication from DDDS to families who are affected and the need for additional information. Wendy asked if perhaps it would help to hold a forum for individuals affected to get their questions answered. Beth suggested we ask the Disabilities Law Program (DLP) to do a thorough analysis of what this will mean for the individuals being discussed, clients who are able to work and earn above the Medicaid limit. Kathie Cherry introduced Cara Wilson from DLP who was attending for Laura tonight. Cara heard a little about the issues in the Policy and Law committee meeting and she has agreed to look into the Lifespan waiver. Wendy asked that we first consider the legal analysis and then decide if an informational meeting is warranted. The committee agreed that this was a good course of action. Cathy said that DDDS needs to have more family meetings and not just about what new services are going to be included in the waiver.

## **CHILDREN AND YOUTH**

Bill Doolittle reported that the committee reviewed its goals and discussed future plans. He shared that the IEP task force is supposed to begin work soon. Bill stated that the Governor continued funding for K-3 basic special education at the same rate as last fiscal year. Bill shared that one of the goals of the committee was to increase the staffing at the Exceptional Children Resource workgroup at DOE. This year DOE asked for three positions and one position was funded. He spoke with and was able to convince the University of Delaware to collect dropout data for students with disabilities. Bill also shared that he would be attending the public forum for the IDEA Part B application review. Discussion ensued around whether that review should be brought directly to Council as we have advisory capacity under IDEA. The changing role of Council was discussed. It was discussed that the DOE now has many groups that they report out to.

## **POLICY AND LAW**

Beth Mineo reported that the group reviewed the recommendations from the legal memo issued on February 7<sup>th</sup>. The committee agreed to adopt all of the recommendations in the memo with the addition of several comments on the medical marijuana regulations. In summary, there were inconsistencies with definitions, many places where there was not adequate elaboration of process or definition so that it would be open to interpretation. The committee offered several suggestions for cleaning the language of the regulation up. A **motion** to take action on the discussed items from committee was **approved with one opposed**.

Commentary on the regulations discussed in committee or approved by the Board was as follows:

### **1. Proposed Division of Public Health Office of Medical Marijuana proposed changes to the Medical Marijuana Code, 22 Del. Register of Regulations 652 (February 1, 2019).**

The Office of Medical Marijuana is making changes to the Medical Marijuana Code. Most of these changes involve the addition of regulations for “Safety Compliance Facilities” to provide quality control testing of medical marijuana and the addition of regulations to permit the production and sale of edible marijuana products at “Marijuana Infused Food Establishments.” Some additional changes are made throughout the Medical Marijuana Code and are discussed in the analysis section. Of particular note, the new regulations restrict the eligible diagnoses for children.

Most of the new regulations appear reasonable, but the regulations are not well-written. While the DLP does not suggest that the councils comment on style and writing as a general matter, the proposed regulations are, in some instances, written so poorly that they become unclear.

#### **I. Permissible diagnoses and physicians** **a. Adults**

For adults, the new regulations add diagnoses of terminal illness, seizure disorder, glaucoma, and debilitating migraines to the list of permitted diagnoses. This was done to make the language consistent with the statutory language at 16 *Del. C.* § 4902A(3)(a).

#### **b. Children**

The current and proposed regulations significantly limit the diagnoses that will allow children access to medical marijuana by creating a separate list of “pediatric qualifying conditions.” It is unclear on what basis the Office of Medical Marijuana imposes the additional restrictions on children. The underlying statute does not contain any such separate restriction. The new regulation reads:

Pediatric qualifying conditions are limited to any of the following related to a terminal illness; pain; anxiety; depression; seizure disorder; severe debilitating autism; or a chronic or debilitating disease or medical condition where they have failed treatment involving one or more of the following symptoms: cachexia or wasting syndrome; intractable nausea; severe, painful and persistent muscle spasms.

It is unclear why diagnoses such as amyotrophic lateral sclerosis (“ALS”) have been excluded for children but included for adults. The regulation is also poorly written and unclear.

As an initial matter, the term “qualifying conditions” is meaningless. This regulation is within the definition of “Debilitating medical condition,” the language found in the statute. The regulation also fails to define “pediatric.” While it may be intended to mean “under the age of 18,” the field of pediatrics extends through age 21 and can be further extended in unusual cases. More importantly, the eligible diagnoses are unclear. As written, it is unclear if “pain; anxiety; depression; seizure disorder; severe debilitating autism” are only eligible if they are “related to a terminal illness.” Sections 3.3.3.1-3.3.3.3 of the new regulation clarify the situation but introduce another problem because those sections include “intractable epilepsy” as a separate eligible diagnosis. While “intractable epilepsy” is probably covered under “seizure disorders,” these regulations need to be consistent and clear. As written, they are neither.

The DLP recommends that the Council ask that the “pediatric qualifying condition” definition and Sections 3.3.3.1-3.3.3.3 be rewritten to be consistent with one another and with the statutory language. Additionally, the DLP recommends that the Council recommend that the availability of medical marijuana for minors should be as broad as possible under the statute. It is unclear whether the additional restrictions on access for minors are even permissible under the statute and, equally important, children whose doctors believe that medical marijuana is the best treatment for them should be able to access that treatment to the fullest extent allowable by law.

There is a similar problem with the definition of “physician.” In the definition of physician, a “physician” for a patient under 18 years of age is limited to certain types of pediatric specialties. In the definition section, the new regulation adds “pediatric psychiatrist” and “developmental pediatrician” to the eligible types of physicians, BUT section 3.3.3 of the existing regulations does not include these new types of physicians to the types of physicians that can certify a minor for medical marijuana. Additionally, the relevant statute, 16 *Del. C.* § 4902A (12) does not include the additions to the types of permissible pediatric specialties. As such, it is unclear whether the Office of Medical Marijuana has the authority to add these specialties at all. The DLP recommends that the Council ask that the definition of “physician” and Section 3.3.3 be rewritten to be consistent with one another and with the statutory language.

## II. Primary Caregiver

Current and new regulations both use the phrase “primary caregiver” in multiple places. The term “primary caregiver” is not defined. It appears from context that “primary caregiver” is being used in place of “designated caregiver,” a term that is defined. The DLP recommends that the Council ask that the regulations be rewritten to use the defined term “designated caregiver” and eliminate the undefined term “primary caregiver.”

## III. Hearing Procedures

The new regulations regarding hearing procedures are not written clearly and may result in persons utilizing medical marijuana being denied access to their medication for a significant period of time even if “expedited” procedures are used. The problematic procedures are the ones used when the

Department determines that a patient's registration card shall be summarily suspended without notice. In such a situation, the patient may request a "record review," but the regulations do not require the Department to act within a certain period of time. The patient may also request an appeal, and can request an expedited appeal. Although the regulations do not explicitly so state, it appears that expedited appeals are only available to resolve summary suspensions. In an expedited appeal, the hearing must be scheduled within 15 days, and the decision on the hearing must be issued with 30 days after the hearing. This means that a person whose eligibility has been summarily suspended may have to wait 45 days for the matter to be resolved. This will likely result in the patient being unable purchase their medication. This is too long a period for a person to be deprived of their physician-prescribed medication without a decision. Additionally, it is entirely unclear how the "record review" and the hearing interact and whether they are sequential processes or can move forward concurrently. The DLP recommends that the Council ask that the record review and hearing regulations be clarified and that the expedited hearing procedures be revised so that a patient whose eligibility was summarily suspended will be able to have a hearing AND receive a decision before they are forced to go without their medication.

#### IV. On Site Visits

The current regulations, in a section that the new regulations do not change, permits on-site interviews of patients or caregivers to determine eligibility for medical marijuana. It is unclear why on-site interviews, as opposed to interviews at a Department office, are warranted. The Department is only required to provide 24-hour notice of an interview. Patients are required to provide "immediate access" to "any material and information necessary for determining eligibility." The requirement to assemble all pertinent information on short notice and have it available immediate inspection may be a significant hardship for persons with mental illness or developmental or intellectual disabilities. The DLP suggests that the Council ask that this section of the regulations be rewritten in such a way that it will meet the Department's needs without placing undue burden and stress on persons with disabilities.

#### V. Service Animals

The new regulations for Marijuana Infused Food Establishments prohibits any "animals/pets" in the establishment "during the preparation, packaging, or handling of any marijuana infused food products. Services animals are not pets, but they are animals. As such, this arguably excludes services animals and persons who need them from Marijuana Infused Food Establishments. It should be noted that the exclusion is for the entire establishment, not just the area where the food is being prepared, packaged, or handled. According to the regulation, a service animal could not be present in the establishment in the area where products are sold to customers if the food products were being prepared in an entirely separate area. The Americans with Disabilities Act (ADA) requires places of public accommodation to permit service animals in most places. It may be appropriate to exclude a service animal from certain areas of the establishment where and when food is being prepared, but a blanket ban on animals anywhere in the establishment at any time food is being prepared, packaged, or handled in the establishment is overbroad. As a federal law, the ADA will preempt this regulation, but the state should not promulgate a regulation that is facially in conflict with the ADA. As such, the DLP recommends that the Council ask that this portion of the regulation be rewritten more narrowly to ensure that it complies with the ADA.

## **2. Proposed DSS Regulation on Application Process, 22 Del. Register of Regulations 652 (February 1, 2019).**

The Division of Social Services (DSS) is proposing to amend the DSS Manual to update the sections on the application process for DSS benefit programs to modernize the language and make it more understandable. For example, the term “food stamps” has been updated to “food benefits.” Most of the proposed changes are not significant substantively, and they do improve the formatting and clarity of the manual. Yet DSS could still make further policy changes to improve the application process and use more accurate terminology concerning language access.

### **Section 2000 and Right to Same-Day Filing:**

The updated version of Subsection 2000(C)(ii) states that DSS will inform applicants of their (1) potential eligibility for assistance; (2) right to an eligibility decision within a reasonable time; and (3) right to appeal any DSS eligibility decision. We recommend that DSS remove the policy of notifying applicants about “potential eligibility for assistance.”

Rather than stating that DSS will inform applicants about their potential eligibility, the DSS Manual should explicitly note that DSS will encourage people contacting a DSS office about benefits to apply on that day. The problem with a policy of informing applicants about potential eligibility is that some applicants might be given erroneous information indicating that they are not eligible for benefits. These applicants might then be dissuaded from completing the application process when they are actually entitled to benefits they critically need. To ensure that DSS is giving all applicants equal opportunity to undergo the eligibility determination process, the DSS Manual should instruct DSS offices to encourage all potential applicants to apply for benefits, regardless of potential eligibility.

### **Subsection 20001.1 and Application Assistance by DSS**

Under Subsection 20001.1(1)(E), “Submitting Applications,” the proposed changes do not adequately address situations in which DSS should help an applicant with the application process. Under federal regulations governing SNAP eligibility requirements, state agencies must ensure that SNAP offices establish procedures that best serve households with special needs, “such as, but not limited to, households with elderly or disabled members, households in rural areas with low-income members, homeless individuals...households with adult members who are not proficient in English....” The proposed language, however, only states that applicants “[w]ill be assisted by DSS in completing the application process if hospitalized or ill.” This policy is too narrow and should be expanded to require DSS to also assist persons who may be elderly, have a disability, be homeless, speak limited English, or otherwise have good cause for assistance.

Additionally, while the current version of the DSS Manual explains that “[i]f an applicant is hospitalized or is ill, provisions for completing the application process at the hospital or in the client’s home will be made by the local intake office,” the revised version no longer includes this explanation. We urge DSS to specify in the updated manual that DSS will make reasonable accommodations to help individuals with the application process, which may include accommodations to allow completion of the application process (including interviews) at the client’s home or other locations.

### **Subsection 2000.2 and Language Access for Limited English Proficient (LEP) Applicants**

The updated subsection on interviewing applicants with limited English proficiency is an improvement over existing policies, but it still requires significant improvement. DSS' revised policies now explicitly state that "DSS will offer translation services to applicants who cannot speak English." They also discuss how the "translator" is "preferably a translator available through the Division's contracted language services."

While CLASI supports DSS' efforts to include policies that clarify that it should offer language assistance services, the proposed language uses incorrect terminology. Translation refers to written language assistance, whereas oral language assistance should be referred to as interpretation. Further, the term "applicants who cannot speak English" is too simplistic and should be replaced with "applicants who are limited English proficient" or "applicants with limited English proficiency." The DSS Manual in Section 1000 already includes an accurate definition of "limited English proficient" that tracks the definition used in federal guidance on language access: "Individuals who do not speak English as their primary language and who have a limited ability to read, write, speak or understand English may be limited English proficient." This distinction in terms is significant because, for example, an applicant might be able to generally speak English but might not understand it well enough to undergo an interview without an interpreter. DSS should also provide an interpreter whenever applicants request one.

The proposed language regarding DSS-provided interpreters is also inadequate. It is unclear what DSS means when it notes that an interpreter will "preferably" be one available through a contracted language service. When would DSS use a non-contracted interpreter? Who would DSS consider to be an acceptable alternative? DSS must also include a policy stating that it will not ask friends or family members accompanying LEP applicants to interpret, nor will it require LEP applicants to provide their own interpreters. DSS' default policy should be to always use certified, trained interpreters.

In sum, Council should support the formatting and updating of the DSS Manual regarding the application process for DSS benefit programs. However, they should ask DSS for the following changes: (1) replace the policy of informing applicants about potential eligibility with a policy of encouraging anyone who contacts a DSS office about benefits to apply; (2) create more comprehensive policies addressing reasonable accommodations DSS will make for applicants during the application process; and (3) use accurate terminology concerning language access policies and specify that DSS will not require LEP applicants to provide their own interpreters.

### **3. Proposed DSS Income Reporting Requirements for Child Care 22 Del. Register of Regulations 658 (February 1, 2019).**

The Division of Social Services (DSS) is proposing to amend the Division of Social Services Manual in order to comply with the new federal statute and regulations regarding reporting requirements for Child Care eligibility. The federal government recently reauthorized the Child Care and Development Block Grant (CCDBG), the federal block grant program that provides child care assistance for low-income families, through the Child Care and Development Block Grant Act of 2014. Additionally, the U.S. Department of Health and Human Services published new rules in 2016 providing further clarification on the 2014 law. Among other provisions, the federal regulations establish limits for when eligible families must report a change in circumstance – such as a change in income – to the



state. These guidelines are meant to reduce the burden of reporting and promote continuity of care. DSS' proposed amendments address these updated reporting requirements.

Under the proposed amendments, families must only report changes when the following occurs: (1) their monthly income exceeds 85% of the state median income (SMI) for the household size; or (2) the family experiences a non-temporary change, including the loss of employment, the completion of an education or training program, or a permanent change in state residency. When a family reports a non-temporary change that ends their need for child care, DSS will authorize 90 consecutive days of child care before case closure.

These amendments could be improved in the following ways:

- DSS must explain how it will ensure that reporting requirements do not place an undue burden on eligible families and accommodate the needs of working parents. Federal regulations mandate that when a state agency, as here, chooses to impose additional notification requirements, these requirements “shall not constitute an undue burden on families” and shall (1) not require an office visit; and (2) be able to be fulfilled through a range of notification options, such as phone, email, online forms, and extended submission hours. The proposed amendments, however, make no mention of how DSS will accommodate families who need to report changes.
- Federal regulations also direct states to take into account regular income fluctuations when the family’s income exceeds 85% of SMI. CLASI previously raised concerns that the DSS Manual lacks adequate explanation as to how DSS will prevent fluctuations in income from resulting in the closure of a child care case. We reiterate that concern here. In November 2018, DSS stated it would be developing more comprehensive and detailed income policies in the near future for child care cases. A more robust income policy addressing fluctuations is needed to ensure that temporary changes do not cause a loss of child care benefits.
- The proposed language about reporting a change in monthly income is imprecise. The proposed policy states: “A family must only report a change in monthly income that exceeds 85% of the state median income (SMI) guideline for the household size.” The policy should instead note that families must only report changes in income that result in their monthly income – not the change in income – exceeding 85% of SMI.
- With respect to the continued authorization of child care for 90 days, the proposed amendments should specify that families will continue to receive at least the same level of assistance during that time period.
- DSS should consider extending the 90-day time period for continued authorizations, or at least allow for extensions for reasons such as disability or other good cause. Federal regulations state that after a parent’s loss of work or other non-temporary change, states must offer families at least three months of continued assistance so the parent can find another job or resume job training or educational activity. The proposed amendments do not discuss how DSS will accommodate families in which a parent/caretaker might have a disability or face other barriers that create a need for a longer job search.
- The amendments should also include a policy explaining how DSS will evaluate whether a family has regained eligibility for benefits before closing a child care case after 90 days of continued authorization. According to federal regulations, “[a]t the end of the minimum three-

month period of continued assistance, if the parent is engaged in a qualifying work, education, or training activity, with income below 85% of SMI, assistance cannot be terminated and the child must continue receiving assistance until the next scheduled re-determination, or at Lead Agency option, for an additional minimum 12-month eligibility period.” DSS should outline how it will ensure continuity of benefits in the circumstances described above. Also, to further promote continuity of care, we urge DSS to exercise the option to approve benefits for an additional 12 months rather than until the next re-determination.

In conclusion, Council should ask DSS to further revise the proposed amendments regarding updated reporting requirements for the child care subsidy program. In addition to making certain language more clear, DSS should develop more detailed policies on the following: (1) how DSS will prevent reporting requirements from becoming an undue burden on families; (2) how DSS will take into account income fluctuations; (3) how DSS will accommodate parents/caretakers (such as those with disabilities ) who may require more than 90 days to find another job or resume job training or educational activity ; and (4) how DSS will evaluate whether a family has regained eligibility before closing a child care case after 90 days of continued authorization.

#### **4. House Bill No. 48- Unit funding for K-3**

The State funds public schools based upon how many “units” of students are enrolled in the school and school district by the last day of September. How many students comprise one unit depends on the student’s grade level, special education classification, and, for some grade levels, whether the student is enrolled for a full day or a half day. 14 *Del. C. § 1703, inter alia*, outlines categories of units, based on grade level, special education classification and full-or-half-day enrollment, and defines how many students comprise one unit. The more students it takes to form one unit, the less funding a school district receives.

The current version of §1703 states that 16.2 students form one Kindergarten through third grade unit unless the student is categorized as requiring intensive or complex special education, at which point one unit is equal to 6 students (intensive) or 2.6 students (complex). The proposed amendment creates a new unit category: Kindergarten through Grade 3 students that are identified as eligible for basic special education and related services. The proposed amendment would, over the course of four years, gradually lower the number of students that would form one K-3 basic special education unit, which functionally increases funding to schools and school districts with students falling into this unit category. Councils may wish to strongly support this amendment, as it will increase funding to schools and school districts with K-3 students that are identified as requiring basic special education and related services.

State funding for school districts and schools is broken down into three categories called “divisions.” Division I money is used to employ teachers, staff, and administrators. Division II is used to finance almost all other school costs. Division III provides additional financial support to school districts. How many “units” of students are enrolled in each school district and school on the last day of September impacts how much a school district and school receive from all three of these pots of money. In other words, the number of units affects multiple factors that will impact student experience, e.g. how many teachers/staff a school can hire and how much money a school will receive to purchase books and materials.

Currently, §1703 contemplates a unit for Grade 4-12 students who are identified as requiring basic special education and related services; each unit is comprised of 8.4 students. However, as mentioned briefly, *supra*, no such category currently exists for K-3 grade students. Currently, one unit is equal to 16.2 students, regardless of whether a student has a disability, unless they are identified as needing intensive or complex special education and related services. This is problematic because students with disabilities, even those that merely require “basic” special education, have additional needs that school districts must address.

There is an ongoing lawsuit alleging that the State is failing to adequately and equitably fund schools, which has resulted in a failure to sufficiently educate students who are low-income, English Language Learners, and/or have disabilities. The lawsuit was filed by the American Civil Liberties Union of Delaware (DE ACLU) and Community Legal Aid Society, Inc., (CLASI) on behalf of two nonprofit organizations, Delawareans for Educational Opportunity, and the Delaware branch of the National Association for the Advancement of Colored People (DE NAACP). One shortcoming in the State’s current school funding scheme that Plaintiffs identified in their complaint is the failure to provide additional funding to schools educating K-3 students who require special education services that are neither intensive nor complex. Delawareans for Educational Opportunity v. Carney, 2018 WL 6175677, at \*14 (Del. Ch. Nov. 27, 2018). The Plaintiffs allege that inadequately funding this category of students resulted in a failure to identify students for special education and related services, delays in creating and implementing Individual Education Programs (IEPs), and lost opportunities to help students catch up academically before they fall “irrevocably” behind.

Creating a K-3 basic special education unit and defining the number of students that comprise one unit below 16.2 students (the number of students that comprise one K-3 unit now) will allow schools to hire more staff and obtain more funding to meet student needs. The proposed amendment will gradually increase funding by lowering the number of students that constitute one unit until it aligns with the Grade 4-12 basic special education unit; 14.2 students will form one unit for the 2019-2020 school year; 12.2 for the 2020-2021 school year; 10.2 for the 2021-2022 school year; 8.4 for the 2022-2023 school year. While it may be ideal if funding increased immediately for the K-3 basic special education unit, any increase is a step in the right direction.

Council may wish to strongly support this amendment. Additionally, Council may wish to offer another suggestion related to funding for students with disabilities. Although this proposed amendment patches a funding hole for one category of students, other children with disabilities that receive services and accommodations under Section 504 of the Rehabilitation Act of 1973 (Section 504) rather than the Individuals with Disabilities Education Act (IDEA) may be being missed. For purposes of Delaware’s education funding statute, whether a student is classified as requiring basic, intensive or complex special education is based upon the IEP and Delaware Department of Education (DDOE) regulations. A review of DDOE regulations suggest that students are only included in a disability unit if they have an IEP. However, not all students with a Section 504 plan will have an IEP. Schools need funding, and teachers and staff to create and implement successful Section 504 plans. It may be good policy for the State to implement a system to ensure these students’ needs are reflected in the unit system, as well.

Council may wish to support this proposed amendment, as it will provide more funding to schools and school districts who teach students between grades K-3 that are classified as requiring basic special

education and related services. Council may also wish to ask the General Assembly to consider ensuring schools receive necessary financial support for students with Section 504 plans who do not also have IEPs.

## **5. House Bill No. 39: Same Day Voter Registration**

This bill establishes same-day voter registration in the State of Delaware. Under current law, voters must register prior to the “fourth Saturday prior to the date of the election.” 15 *Del. C.* §2036. This bill changes the deadline to the day of the election and specifically permits voters to register at their polling places by submitting an application and identification with proof of address at the polling place. The bill permits multiple forms of identification including (1) government issued photo identification, utility bills, bank statement, paycheck, and similar documents. The bill also changes the deadline for registrations that are mailed or completed by agencies other than the Department of Elections to require that the registrations be received prior to the deadline (i.e., prior to election day). Voters will still be able to register to vote in advance of the election using all of the means that presently exist.

Although not specifically targeted toward persons with disabilities, this bill will benefit persons with disabilities. The current registration deadline is a significant distance from election day. This can cause persons who might want to register to miss the deadline if they are unaware of the registration deadline. Unlike the date of the election itself, the voter registration deadline is not nearly as well publicized. This bill will prevent that problem. Additionally, the current system requires a two-step process: (1) registration and (2) voting, that occur at separate times and places. Allowing both parts of the process to be completed at the same time and place (i.e., the polling place on election day), eliminates some of the burden on voters. For voters who prefer to register in-person, the ability to do so at their polling place on election day will make the registration process much easier.

Although the minimization of administrative burdens is a good thing, the implementation of same-day voter registration may create accessibility problems for voters with disabilities. Voters attempting to register to vote on election day may require assistance from poll workers, and some voters may require the registration materials in accessible formats. It will be extremely important for the Department of Elections to consider accessibility when it establishes its procedures for same-day registration at polling sites.

Anything that removes or minimizes administrative burdens to voting is a benefit. For voters with disabilities that cause those administrative burdens to be more burdensome than they are to the average voter, the elimination of the burden is an added benefit. For this reason, the DLP recommends that the Council support this bill and should include in the statement of support a statement noting that it is vitally important for the Department of Elections to consider accessibility when it establishes its same-days registration procedures.

## **6. Senate Bill No. 17: Insurance discrimination based on genetic information**

Senate Bill 17 increases the protection provided by the Genetic Information Nondiscrimination Act of 2008 (GINA). GINA protects individuals from genetic discrimination in health insurance (TITLE I) and employment (Title II).

Specifically, health insurers cannot use genetic information to make decisions about eligibility, coverage terms, or premiums. Health insurers may not request or require individuals to undergo genetic testing; consider family health history or a genetic test result as a pre-existing condition; or to use any genetic information they have to discriminate against the individual.

GINA does not apply to the following: federal employees who receive medical care through the Federal Employees Health Benefits Plans; members of the military who receive care through TRICARE; veterans who receive care through the Veterans Health Administration; and Native Americans who receive care through the Indian Health Service. In addition, GINA does not cover long-term care insurance, life insurance, or disability insurance.

Employers cannot use family health history and genetic test results in making decisions about an individual's employment. Specifically, employers cannot use genetic information in employment decisions such as hiring, firing, promotions, pay, and job assignments. Employers are also prohibited from requesting genetic information or genetic testing as a condition of employment.

GINA provides the minimum level of protection against genetic discrimination. However, states can provide more protection against genetic discrimination. Senate bill 17 is an attempt to broaden GINA to prohibit genetic discrimination in the issuance or renewal of disability insurance and long term care insurance. The bill would amend 18 *Del. C.* §2317. The bill provides that if an insurer requires a genetic test, notice that a test is required be given to the individual. Written authorization to perform the test is also required. The bill applies to everyone seeking disability or long term care insurance.

The bill has a noticeable shortcoming, namely that it does not apply to life insurance. The same arguments that have been advanced with respect to disability and long term care insurance apply equally to life insurance. If life insurance companies were prohibited from using the genetic test results of applicants, genetically at risk individuals would be more willing to have genetic testing. This could lead to earlier medical treatment, resulting in improved health and increased life expectancy of the affected individuals. Other states, including Arizona, Maine, and New Jersey, prohibit genetic discrimination for life insurance and disability insurance policies without actuarial justification. Massachusetts, Montana, and New Mexico prohibit genetic discrimination for life, disability, and long term care insurance policies.

Council should consider asking the bill's sponsors to amend the bill to also prohibit genetic discrimination in the issuance or renewal of life insurance policies. This would give greater protection to all those individuals who want to have or are considering having genetic testing.

## **7. Raise the Wage Act, H.R. 582 and S. 150 [January 16, 2019]**

Congress has introduced the Raise the Wage Act (H.R. 582) in the United States House of Representatives and a companion bill (S. 150) in the United States Senate. This legislation proposes raising the federal minimum wage to \$8.55 this year and increases it over the next five years until it reaches \$15.00 an hour in 2024. After 2024, this legislation would adjust the minimum wage each year to keep pace with growth in the typical worker's wages. Most relevant for people with disabilities and disability advocates, this legislation would phase out the allowance provided to employers to pay workers with disabilities subminimum wages.

The Fair Labor Standards Act allows employers to pay employees with disabilities “whose earning or productive capacity is impaired by age, physical or mental deficiency, or injury” wages below the minimum wage by applying for special certificates. The Raise the Wage Act gradually eliminates the subminimum wage by increasing wages for workers in employment establishments with a special certificate gradually to \$12.85 per hour five years after the passage of the act. As of the date of passage, no new certificates could be issued to any employer that had not already received a special certificate prior to the passage date. Six years after the Act would take effect, all certificates would expire and would have no legal effect.

Proponents of the special certificates created by the Fair Labor Standards Act argue that it offers workers with disabilities a foot in the door of the labor market and gives them the opportunity for skill development, training, and an upward career trajectory. Supporters also fear that the elimination of the subminimum wage means that workers with disabilities will likely receive no wages and will face obstacles in the general labor market.

In reality, the subminimum wage stigmatizes and discriminates against workers with disabilities by devaluing their work and eliminating basic labor protections afforded to other individuals and leaves workers with disabilities vulnerable to abuse. The special certificate policy exposes workers with disabilities to exploitation and seclusion by creating “sheltered workshops, which employ people with intellectual and developmental disabilities to perform manual labor while paying employees as low as less than one dollar per hour.” Addressing the argument that the elimination of sheltered workshops will cause harm to workers with disabilities, statutes and case law exist to prohibit employer discrimination and require reasonable accommodations in the workplace.

In 2016, the Department of Labor’s Advisory Committee on Increasing Competitive Integrated Employment for Individuals with Disabilities recommended phasing out the separate subminimum wage. A 2012 report from the National Council on Disability also supported gradually phasing out the use of special certificates under the Fair Labor Standards Act. While passage of the Raise the Wage Act is preferable to maintaining the status quo, Council should consider questioning the lengthy implementation process and ask why a gradual approach is more necessary than providing a livable wage to workers with disabilities as quickly as possible.

#### **8. DMMA Proposed Renewal of DDDS Lifespan Waiver, 22 Del. Register of Regulations 697 (February 1, 2019).**

The Division of Medicaid and Medicare Assistance (DMMA) gave notice that it intends to file with the Centers for Medicare and Medicaid Services (CMS) for a five-year renewal of the Division of Developmental Disabilities Services (DDDS) Lifespan Section 1915(c) home and community based services waiver. The waiver was recently substantially amended to include services for individuals living in family homes. The DDDS waiver historically only serviced individuals living in residential placements.

The most significant changes are as follows:

- The waiver adds a new service, which is Medical Residential Habilitation. DDDS is extending eligibility for residential habilitation to individuals who require medical supports.

- Language allowing individuals enrolled in the DDDS Lifespan to also enroll in Section 1115 DHSP Waiver “in order to receive their acute care benefits”
- New provider types have been added

Primary evaluation is restricted to Appendix C, which describes Participant Services. DLP makes the following observations regarding the proposed additions:

Residential Habilitation. DDDS is adding a new category called Medical Residential Habilitation which is described as “include[ing] the provision of direct skilled nursing services and habilitative services and supports that enable a participant to acquire, retain or improve skills necessary to reside in a community-based setting.” These services can be provided in group homes, a supervised or staffed apartment or a shared living arrangement. Residents would be required to need medically necessary direct skilled nursing services that must be performed by an RN or LPN within scope of practice, ordered by a physician. These nursing services must be needed daily and not be amenable to pre-scheduled visits. Nursing services can be provided up to 24 hours a day if necessary; the waiver also says that providers can use one nurse to support more than one person if appropriate. Budgeting language in Appendix I-2 suggests that DDDS will allow staffing of one nurse for three residents in a neighborhood home, and one nurse for two residents in a CLA or SLA. The provider is required to oversee the health care needs of the participant.

Council may wish to express concern about the following points:

- Shared living arrangements and community living arrangements are not licensed by any health care organization. Neighborhood homes are licensed by DHCQ. SLAs are “credentialed” by DDDS but hands on, direct oversight is minimal. Is it safe to allow skilled nursing services to be provided by in places that are not licensed or overseen by agencies with experience in the provision of health care services?
- A later section indicates that in SLAs that provide Medical Residential Habilitation, the provider must be a registered nurse or an advance practice registered nurse. Councils may wish to question who is providing medical supervision to these nurses or to nurses in other settings. The language suggests that the providers are responsible for overseeing health care. Do the providers have medical directors or a doctor on staff who will provide supervision? If not, who is providing supervision to the medical aspects of care? In the CLA or SLA setting, who is supervising the medical aspects of care?
- The waiver language indicates that nurses providing services in Medical Residential Habilitation “demonstrate the ability to work with individuals with ID/DD with a wide range of intensity of support needs.” There is no discussion of who assesses for this degree of experience nor is there an indication that DDDS will develop specific credentials for these nurses.

Provision of this service will enable some individuals with intellectual disabilities to live in more integrated settings by providing skilled nurses in non-nursing home settings; however, it remains important for there to be sufficient oversight of the care that is provided in this setting, and the waiver document is very short on details on how this will be achieved. SLAs and CLAs should be a particular source of concern because they are not licensed by a health care agency. While there is some utility in

getting out from under rigid health facility licensing requirements, it is equally important not to swing so far in the other direction that there is minimal oversight of medical care.

Also related to Residential Habilitation, the waiver states that this service can be provided out of state. The language indicates that DDDS remains responsible for assuring the health and welfare of out of state placements even when onsite monitoring is being done by the local authority. Council should suggest that DDDS have an articulated robust policy regarding oversight of residents placed out of state. Such a policy is not evident in the waiver (although it may not be the place for it).

Finally, there is language that indicates that “individuals under 21 must access services through EPSDT before the waiver can be accessed.” Early Periodic Screening, Diagnosis and Treatment (EPSDT) services do not always cover residential services, especially for those who do not carry a behavioral health diagnosis. How are children and youth under 21 to access this service through the Lifespan Waiver? DDDS must recognize that it has a role in providing services to individuals under 21 with ID/DD and that EPSDT services, which often lack care coordination, may not always be a source of comprehensive services for young people with ID/DD.

Home Modifications. Language has been added to allow payment for generators as a home modification under the waiver. Additional language clarifies that providers of this service need to be bonded, insured and have all necessary permits and licenses required by trade. They must also provide a one-year warranty for any work done. Council should consider endorsing these changes.

Supported Living. The waiver adds language requiring supported living providers to be qualified by DDDS and meet DDDS standards. They must also agree to comply with PM46 and other abuse and neglect processes. Direct care workers are required to be certified through completion of a training program as required by DDDS.

Concurrent Participation Language was added to allow participation in multiple waiver programs. Lifespan Waiver participants will now be able to enroll in DSHP plus for “non-DDDS Lifespan Waiver acute care benefits.” This allows all participants to get non-DDDS services through Medicaid managed care. This may enable participants to access a broader range of providers.

## **MEMBERSHIP COMMITTEE**

Bill expressed his concern about our compliance and he has asked staff for an updated membership list. Ann introduced Sarah Marlowe, who is a new applicant to Council.

## **PERSONNEL COMMITTEE**

The committee had nothing to report.



## **AD HOC COMMITTEES**

No report.

Ann announced visitors for the evening as well as members who advised us that they would not be in attendance today. She advised members that copies of all letters and responses are available for viewing at the back of the room.

A **motion** was made **to adjourn** the meeting. The **motion** was **approved**. The meeting was adjourned at 8:04 p.m.